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The Effectiveness of Italian Law 104/92: Healthcare for Pediatric Physical Disabilities

Claudia Heim

CISLA Independent Study

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1. Introduction

Understanding the Italian National Healthcare System, *il Servizio Sanitario Nazionale* (SSN), established in 1978, is an important topic because of how it operates a national system available to all its citizens, a structure that has been difficult for other countries, such as the United States, to achieve. It is important to understand its positive achievements, such as providing reliable and affordable care to its citizens, but also its downfalls, such as long wait times for tests, procedures, and doctor visits. Its dual system of public healthcare along with private healthcare, which often work together, offers an interesting template to study. Furthermore, it is important to understand how this dual system cares for individuals with long-term conditions, especially those who are physically disabled.

According to the World Health Organization, over one billion people have a disability and they are highly at risk to experience inadequacies with a provider or facility, and more likely to be denied healthcare (“Better Health for People with Disabilities”). Although Italian healthcare is highly ranked globally, infrastructural issues clearly affect the care of its citizens. This paradox leads to the question of how this might affect individuals who need immediate attention, such as a child with a physical disability.

Law 104/92 defines a person with a disability as, “a person with a physical, mental, or sensory impairment, who is stabilized or progressive and has difficulties with learning, relationship or work integration and is at a social disadvantage.” It was established to provide adequate support to the disabled person and his or her family to achieve the autonomy and social integration of the disabled individual (“Legge 104 per Disabili.”) and was revolutionary in formulating a comprehensive definition for the disabled and their rights to care (Massi, 14). The law provides assistance within the SSN for both health and social services, such as rehabilitation

(“Legge 104 per Disabili.”). However, after spending some time immersed within the construct of the SSN, the pitfalls of public initiatives similar to those outlined in this law became clear, such as funding and staffing issues. As previously stated, the focus of this paper is children with physical disabilities, but Law 104/92 includes a broader definition. Narrowing the scope of the type of disability offers a more focused and in-depth analysis into the specific functions of this particular law. With these ideas in mind, this investigative paper has two aims: 1) to analyze the effectiveness of Law 104/92 in the care of children with physical disabilities, a law which strives to help those with disabilities achieve autonomy within society and 2) to further demonstrate the healthcare for these children in a case study at Fondazione Santa Lucia, a rehabilitation center in Rome, Italy.

2. The Structure of the Italian National Healthcare System

1. (I principi). - La Repubblica tutela la salute come fondamentale diritto dell'individuo e interesse della collettività mediante il servizio sanitario nazionale.

La tutela della salute fisica e psichica deve avvenire nel rispetto della dignità e della libertà della persona umana.

Il servizio sanitario nazionale è costituito dal complesso delle funzioni, delle strutture, dei servizi e delle attività destinati alla promozione, al mantenimento ed al recupero della salute fisica e psichica di tutta la popolazione senza distinzione di condizioni individuali o sociali e secondo modalità che assicurino l'eguaglianza dei cittadini nei confronti del servizio [...] - Legge 833/78

1. (The Principles). - The Republic protects health as a fundamental right of the individual and as a collective interest through the national health service.

The protection of physical and mental health must take place with respect for the dignity and freedom of the human person.

The national health service is made up of all the functions, structures, services and activities for the promotion, maintenance and recovery of the physical and mental health of the entire population without distinction of individual or social conditions and in ways that ensure the equality of citizens within the service [...] - Law 833/78

I. A Brief History of the Current Healthcare Structure

During the 1930s (“Timeline of Healthcare in Italy.”), before the national healthcare system was enacted in 1979 (Vicarelli, 157), the SSN was based on mutual bodies, responsible for insuring workers, as well as their family members. These funds paid for any medical need and were financed by contributions made by the workers themselves. Therefore, the right to health insurance was not the fundamental right of a citizen, as it is today, but rather it was the right of the worker. As a result of this distinction, there was a wide lack of coverage during this time for those who did not work.

This structure changed in 1958 when the Ministry of Health (*Italia il Ministero della Sanità*) was established under Law 259 under the government of Fanfani II. This ministry was split from the Ministry of the Interior and Vincenzo Monaldi was appointed to oversee the department. Then, in 1968 the Mariotti Law was established (number 132) to reform the hospital system because, up until this point, most hospitals were managed by charitable organizations. These were thus converted to public bodies, or hospitals, which were reorganized under new regulations, now planned and financed at the regional and national levels. Then, in 1974, Law 386 dissolved the mutual bodies and their board of directors, transferring the responsibility of the hospitals to the regional governments. Finally, in 1978 under Law 833 the mutual system completely ended, and *il Servizio Sanitario Nazionale* was established and active by the 1st of July 1980 (“Servizio Sanitario Nazionale (Italia).”).

II. Government Division of Care Responsibilities

The responsibilities of the healthcare system is divided up into three basic levels. The top level is at the national level, followed by a structure at the regional level, and final organization at the local level.

The national level, controlled by the Ministry of Health (Vicarelli, 157), is responsible for collecting and disbursing the public's taxes to fund the public health institutions.

Additionally, this level is also required, by the constitution, to determine the health services to which each citizen is entitled (Donatini). These services are outlined in LEA, *i Livelli Essenziali di Assistenza* or the Essential Levels of Care ("Cosa Sono i LEA.").

The second level below this is the regional level, which is comprised of the regional health departments (*assessorati regionali alla sanità*) (Vicarelli, 157). These departments are in charge of their local health units and how they deliver care, including setting payment rates for hospital and outpatient specialist care (Donatini).

The last level is the local level, ASL (*Azienda Sanitaria Locale* or Local Health Unit)¹, made up of 78 hospital trusts (*aziende sanitarie ospedaliere*) and 143 local health authorities (*aziende sanitarie territoriali*) (Vicarelli, 157). They serve to pay for the care of each patient with tax money, which is distributed by the region to the local level. As an example of how this works, a patient will go to a doctor's visit and the doctor may prescribe a wheelchair for a child who has a walking disability. This prescription will get sent to an ASL office, where an official will read the diagnosis and notes taken by the physician before signing off on the prescription. Once this happens, the patient will have the wheelchair, fully paid for by the public healthcare system.² The local level is in charge of providing primary care, hospital care, outpatient specialty care, public healthcare, and social care to Italian citizens (Donatini). Also at the local level are hospital personnel. It is important to note that although these individuals have a contract to work for the government for the SSN, general practitioners and pediatricians are still free professionals (Vicarelli, 157).

¹ Information obtained through observation during an internship at Fondazione Santa Lucia, June-July 2019.

² Observation June-July 2019.

III. Public Funding

In Italy, 80% of citizens visit public hospitals. If an individual pays taxes, then he or she is insured under public healthcare. This is because a percentage of one's income goes toward *tassa della salute*, which is a tax on healthcare, therefore, this is how public healthcare is paid for in Italy.³ However, if an individual cannot afford to pay taxes, then care is still required to be provided as the system is technically free.⁴ Public healthcare is mainly funded by corporate taxation. This means that the tax is collected at the national level and then redistributed back to the regional level. There is an additional fund in which the government collects through taxes and gives to regions that lack sufficient resources to provide LEA to patients. Lastly, the local health units are funded by capitated budgets (Donatini), meaning that the physician's salary is based on the number of patients he or she sees (Park, M., Braun, T., Carrin, G., Evans, D., 2007).

IV. The Services Covered and How Patients Pay for Care

The required services to be provided under the SSN are outlined in LEA (*Livelli Essenziali di Assistenza* or Essential Levels or Care). These levels of care are provided in an updated version outlined in the Ministerial Decree of the 12th of January 2017. This decree actually has replaced the care levels outlined in the very first decree from 2001.

There are three defined levels of LEA. The first level of care is the “collective prevention and public health,” which includes initiative such as, the prevention of infectious diseases, outlines for vaccination programs, food safety, safety in the workplace, and animal health and veterinary urban hygiene. The second level is “district assistance,” which organizes the health and social-health services in the territory such as basic care, emergency care, supplementary

³ Morelli, Frida. Ongoing communications at Connecticut College. September-December 2019.

⁴ Sorcini, Andrea. Interview. 18 January 2018.

assistance, and residential health and social assistance. The third outlines “hospital assistance,” including first aid, hospitalization, day surgery, rehabilitation, and transplants. Services provided by the regions beyond what is outlined in LEA is dependent on the regions’ resources. Therefore, the objective of this legislation is to make the required health services more uniform across regions, as well as better allocate the resources needed in order to provide these services to patients (“Cosa Sono i LEA.”)

The services outlined above are either free or are paid for by the patient based on a small fee, or *ticket*. The *ticket* is like a copay for the service, but it is based on income. Therefore, some patients will be given a lower fee than others. In other cases, the patient may have to pay a more expensive copay, which can sometimes cost as much as getting the care privately.⁵ All patients must do when they go for a regular appointment is show their social security number; they do not need a credit card or an insurance card.⁶ Also included is free medication, called *salva vita*, which is deemed necessary for inpatient care. However, patients must pay a copay for medications deemed unnecessary, as well as pay for over-the-counter medications.⁷ Additional services include preventive medicine, primary care, outpatient specialist care, home care, and hospice care (Donatini).

Although many costs are covered, there is also a system of cost-sharing. Cost-sharing requires a co-payment made out-of-pocket by the patient. Instances that need a co-payment include each prescribed procedure or specialist visit that a general practitioner or specialist prescribes. Currently the standard price is EUR36.15 (USD48.00). Examples of these types of

⁵ Morelli, September-December 2019.

⁶ Sorcini, 18 January 2018.

⁷ Sorcini, 18 January 2018.

procedures and visits are an MRI or a visit to a gastroenterologist. Co-payments are also applied to outpatient medicine (Donatini).

There are specific groups of individuals who are exempt from this cost-sharing system. These groups include individuals under 6 and over 65 living in households with a gross income below the national threshold, prisoners, individuals with HIV, and pregnant women. Additionally, most screening services are free. More pertinent to this study is that the disabled and individuals with chronic and rare diseases are also exempt from co-payments (Donatini). The children that visit Fondazione Santa Lucia fall under this last category and thus their families pay next to nothing for the children's care, including devices such as walkers and wheelchairs, as well as tests such as X-rays.⁸

V. Divisions of Patient Care

There are also several care divisions. The first of which is primary care. As mentioned, primary care is free under the SSN and is made up of self-employed and independent physicians, general practitioners (GP), and pediatricians who are paid under contract by the government by capitation. Local health units will also give additional money for the delivery of specific services such as home care. Patients may choose whichever physician that has not reached his or her max number of patients (1500 for GPs, 800 for pediatricians). The role of a GP is determined based on agreements made between the central government and the GP trade unions.

A second division of care is outpatient specialist care, which is provided by the local health units or by the public or accredited hospitals (Donatini). An accredited hospital is a private hospital that has been accredited by the SSN and follows the same guidelines as a public institution.⁹ These physicians are also self-employed under contract with the SSN and are paid

⁸ Observation, June-July 2019.

⁹ Observation, June-July 2019

hourly. Outpatient specialists can also see private patients in comparison to specialists who work for the local health units and public hospitals who cannot see private patients. However, public physicians can see private patients using public hospital facilities for extra income, but a portion of this must be given back to the hospital. The patient has the choice to seek care from a public or accredited hospital once he or she has been given a referral for a visit, treatment, or test, but is not able to choose the physician. Hospitals, both public and accredited, are publicly funded by the local health units, which also often manage these hospitals (Donatini). Fondazione Santa Lucia is an accredited hospital. Additionally, the children who come for therapy at the Pediatric Extensive Rehabilitation Center are outpatients, therefore this section outlines how the services in this department function at this particular site.¹⁰

Patients can also receive long-term care and social supports (Donatini), a hallmark of the integrated healthcare approach of the Italian healthcare system, vital for the care of patients such as children with physical disabilities. Patients can be treated in residential and semi-residential facilities which provide physicians, nurses, therapies, and assistive devices, or they can receive care at home. The method of payment is again a cost-sharing method and it is based on the patient's income. There are other options including community care, which provides assistance during a patient's treatment or therapy and is publicly funded. Some ways of helping with the cost of care are provided such as accompanying allowances and care vouchers, as well as voluntary organizations (Donatini).

VI. Private Healthcare

Private healthcare has a limited role in the SSN. In 2014, it was only 1% of the total spending and only about 6 million people were covered under a form of voluntary health

¹⁰ Observation, June-July 2019

insurance policy (VHI). This low percentage is due to the fact that Italian citizens are not allowed to be solely covered by private health insurance, however supplementary private care is available (Donatini). Private healthcare is for patients who do not want to wait in the long wait times the public system is so often faced with, but who can also afford the fast treatment. These patients also have the choice to see the doctor they prefer. Sometimes the wait can be tomorrow in a private hospital, versus a year in a public one.¹¹ Other benefits of private healthcare include a higher level of comfort and privacy in hospitals. Additionally, certain policies will cover the co-payments for private services or provide a daily compensation for extended hospitalization. The care provided to the children at Santa Lucia is not private, however, private care is available in other parts of the hospital and it is important to discuss this type of care in order to have a complete understanding of the Italian healthcare system.

There are two types of private insurance: corporate and non-corporate. Corporate insurance is insurance that is provided by companies to their employees, which can also benefit their families. Non-corporate insurance is bought independently by an individual as supplementary insurance for him or herself and the family. Private insurance is mainly provided by non-profit organizations, such as voluntary mutual insurance organizations, corporate funds, and collective funds, but can also be supplied by for-profit organizations. The nonprofit organizations are organized by employees or professional associations for their employees or members (Donatini).

Although these may be nice perks, someone who needs critical care would not go to a private hospital. In fact, as far as resources, private hospitals are not always better than public ones. For example, private hospitals need permission for more activities from the government

¹¹ Sorcini, 18 January 2018.

and they often cannot accommodate big surgeries. Some private hospitals do not even have blood banks and they have to send samples to public hospitals for testing.¹² This most likely results from private hospitals being more specialized, such as the case of Santa Lucia, which is strictly a rehabilitation hospital.

VII. Checks for Quality of Care

As with any healthcare system, there must be checks in place to ensure the quality of healthcare. This is the responsibility of the national and regional governments. In addition to the quality of the care, the LEAs must be maintained and the wait times for patient visits must be monitored. To combat these wait times, some regions are implementing prioritizing the delivery of care and services based on patient severity.

There are a few ways in which the SSN also ensures the competence of the physicians and other staff members. One example of this is the certification of those working under the SSN. All working members must be certified and participate in further education. There is also the National Commission for Accreditation and Quality of Care, which is responsible for making the criteria that guides how to select providers, as well as evaluate regional accreditation models. Health service charts outline areas such as service performance, quality indicators, waiting times, quality assurance strategies, and the patient complaint process. Public hospitals are required to issue these, as well as accredited hospitals. There are disease management programs and the National Plan for Clinical Guidelines (*Piano Nazionale Linee Guida*) which contain guidelines for proper care procedures in areas such as cardiology, cancer, and antibiotics (Donatini).

¹² Sorcini, 18 January 2018.

VIII. Negatives of the Healthcare System

Italy's healthcare system has high levels of appropriateness, accessibility, satisfaction and health but, the great territorial and social imbalances cause problems of equity and equality within the public healthcare system (Vicarelli, 174). Interregional disparities are still a concern in Italy as the South continues to be less affluent than the North. This spills into the healthcare system, as well. Further fueling this is the fact that regions receive an amount of money based on the proportion of what they contribute through taxation. This system causes gaps in care to arise, resulting in regional divides (Donatini). Gaps also arise due to the poor allocation of money by government officials, which can result in a lack of hospital resources. The South in particular has dealt with government corruption since the 1870s which has contributed to the lack of progression. There have been laws in place which have tried to push for progress, but the main problem is the political corruption in decision-making and funding. The government money may remain with the government officials rather than benefiting the people.¹³ Although the government has funds to give to regions who are struggling to provide LEA, the money may not be allocated properly. Furthermore, regions can also generate additional revenue on their own and provide services beyond what is outlined in LEA, however, this also adds to regional inequalities (Donatini) depending on the wealth and resources of one region compared to the others.

In hospitals in the South there is a smaller number of beds, decreased availability of advanced medical equipment, fewer public versus private facilities, and less developed community care facilities. This gap continues to increase and the income related disparities are significant. In order to try and combat these inequalities, regions receive a proportion of funds

¹³ Sorcini, 18 January 2018.

from the equalization fund, *Fondo Reriquativo Nazionale*. The Ministry of Economy and Finance aggregates funding to the regions, which is decided based on the capitation and adjusted for demographic characteristics and use of health services based on age and sex. However, there is no systematic public reporting for variations in health and health access between regions, but several public and private institutions publish reports to analyze these healthcare differences.

Furthermore, Italy's debt is one of the highest among the world's industrialized nations (Donatini), which would be concerning in maintaining public programs such as healthcare. When discussing some of the financial concerns of running public initiatives with Dr. Morelli of Fondazione Santa Lucia, she spoke of a concept called *i soldi in nero* (black money). This "black money" means that when an individual performs a job, he or she is paid in cash and under the table and therefore does not have to pay taxes on the income.¹⁴ This also means that these individuals are not contributing money to the government to help pay for the healthcare services, money is lost, and public healthcare becomes difficult to fund.¹⁵ Italians pay 50% income tax, therefore when multiple individuals do not contribute this money to the infrastructure of the country, there is a significant impact (Bezzone). The central government can, however, set in place recovery plans in regions with expenditure deficits with plans such as revising hospital and diagnostic fees, reducing bed numbers in the hospital and increasing copayments for pharmaceuticals (Donatini). However, this could very well backfire on regions that are already struggling to make ends meet.

There is also a fragility in regulatory structures. The main cause for this is the various conflicting interests, both political and economic. Additionally, the regionalization process is poorly coordinated at the national level, exacerbating local disparities. There is also disparity in

¹⁴ Observation, June-July 2019.

¹⁵ Observation, June-July 2019.

equality and availability of healthcare governance, which causes marginalization of planning and the control of decisions by citizens and medical and healthcare professionals. The failure to involve doctors into management organization leads to a rise in political control of certain parts of the medical profession and thus causes a growing dissatisfaction with the SSN. This is not good as it is important to have healthcare professionals in positions of management because they can adequately respond to patient needs (Vicarelli, 174).

Overall, the healthcare system in Italy is well planned out and is organized in such a way to offer patients stable care. However, due to regional disparities in the country and poor allocation of funds, the care cannot always be executed in the way in which it was intended. This is an important theme to keep in mind moving forward as it very much relates to the realities of the care of children with physical disabilities in comparison to the goals of the legislation.

3. Background on the Internship Location: Fondazione Santa Lucia

Fondazione Santa Lucia was the internship location that was the backdrop for much of the research conducted for this project. Understanding its history and place within Italy's national healthcare system as an accredited hospital also demonstrated the care children with physical disabilities receive. Furthermore, observational learning was conducted in the Pediatric Extensive Rehabilitation department, which provided the perfect case study for full comprehension of care.

I. History of the Foundation

Fondazione Santa Lucia was established in 1960 as a residential center for rehabilitation called *Il Centro Residenziale per la Riabilitazione "Oasi"*. They focused on treating patients with motor and neurological conditions from World War II ("Our History."), which was a common practice during this time as hospitals started out as charitable organizations ("Servizio

Sanitario Nazionale (Italia).”). Since the center was established, it has continued to progress and lead the field in neuroscience, both in Italy and internationally (“Our History.”).

Starting in 1991, Santa Lucia began to take on more teaching opportunities to provide degree programs and internships in partnership with various universities. In 1992, the Ministry of Health recognized Santa Lucia as a Scientific Hospitalization and Treatment Institute (*Istituto di Ricovero e Cura a Carattere Scientifico*) (“IRCCS: Scientific Institute for Research, Hospitalization and Healthcare.”). Institutions accredited to be IRCCs began in the 1930s. Interestingly, this accreditation began in reaction to the establishment of the National Institute of Health in the United States (“Our History.”). Therefore, this is Italy’s version of promoting medical research to progress in the scientific field within the country. In 2003, the Legislative Decree 288 was established in order to federally regulate the activities conducted by the IRCCs (“Our History.”). This accreditation gives social importance to centers that specialize in the treatment and research of specific medical issues (“Our History.”). It is a way to allow centers, such as hospitals, to continue researching, but also validate their work in the scientific community. Through this, the foundation became the first to be accredited in the field of neuroscience and has become a leader in the medical field, now a part of a network of neuroscience specialized IRCCs. Santa Lucia continually makes research a fundamental part of the hospital’s work (“IRCCS: Scientific Institute for Research, Hospitalization and Healthcare.”). The research they conduct also fosters partnerships with over 100 other universities and research centers, both in Italy and abroad (“Our history.”).

There are five specific fields in which Santa Lucia researches in: clinical and behavioral neurology, innovative methodologies for rehabilitation, preclinical neuroscience, cognitive and motor neurorehabilitation and neuroimaging, and translational clinical research (“Research

Lines.”). Specifically the methodologies for rehabilitation and cognitive and motor neurorehabilitation would be important for the Pediatric Extensive Rehabilitation Unit. Many of the physicians conduct clinical research as they can include the work they do with their patients as part of their research. This includes trying to understand the effects of certain devices in therapy, as well as uncover the best ways to approach cognitive and speech therapies.¹⁶

Santa Lucia is also a part of various government programs including the Italian Advance Translational Research Infrastructure (IATRIS) and the European Advanced Translational Research Infrastructure in Medicine, which are a part of the Italian National Institute of Health (*Istituto Superiore di Sanità*) (“IRCCS: Scientific Institute for Research, Hospitalization and Healthcare.”).

In 1998, *Centro Residenziale Clinica Santa Lucia* became *Fondazione Santa Lucia*. The name change came after a statute decree was passed which re-established the goals, responsibilities, and laws of the hospital. The two main ideals Santa Lucia stands by are assistance through care and rehabilitation, but also non-profit research in neuroscience. In 2002, the services provided at Santa Lucia were affirmed to be provided in accordance with *il Servizio Sanitario Nazionale*. However, private care is also available at this hospital (“Our History.”).

Although Santa Lucia provides services under the SSN, it is still a private hospital and offers private care in addition to its public care. Because the hospital offers both types of healthcare, this provided a unique experience as an internship location in understanding how private and public care function in the same system. This is possible because Santa Lucia is an accredited hospital. An accredited hospital, as mentioned in the previous section, is a hospital owned privately, but under compliance with the regulations of the public health system and thus

¹⁶ Observation, June-July 2019.

also provides public care.¹⁷ For example, both public and private institutions must comply with articles 41 and 43 of the constitution (Mori, 2015), which mainly create checks and balances of the private institutions so that they are still run in the interest of the public (Constitution of the Italian Republic). The care provided in both the private and public sectors, therefore, must be comparable.

The first step in accreditation is authorization, which ensures that the institution is following Law 502/92, and is thus meeting the goals set out by the SSN. The next step is the actual accreditation within the SSN. This step defines a completely private institution from an accredited one. If an organization only wants to provide services within the private sector, then it will only have to pass through authorization. An institution will be accredited with compliance to the health planning and other regional requirements based on the Legislative Decree 59/97, which will then allow the institution to operate for the SSN. The hospital is required to use the same rate for services, including co-payments and will receive some additional funding at the regional level. There are strict follow-up procedures for accreditation including a contract and periodic checks of the services being provided to ensure the quality of care (Mori, 2015).

Private care comes into play in a variety of forms at Santa Lucia. One example is hospitalization because the sixth floor of the main hospital is dedicated solely to patients with private care. These patients may have wanted faster treatment, more comfortable care, or even to be able to choose the preferred hospital and physician, as private care allows. Additionally, Santa Lucia provides a private rate for X-rays and other forms of tests. In the public sector it can be difficult to have tests performed in a timely manner due to long wait times. Therefore, some people opt to get these tests performed in the private sector, especially if it is urgent. There is a

¹⁷ Observation June-July 2019.

set price for the test at the hospital, such as an MRI that costs 70 Euros. What is interesting to note about this price, however, is that it varies between hospitals, creating a kind of market for competitive prices. One hospital may offer a lower price for a test than another. However, if a patient does wait to have the test performed in the public sector then it will be cheaper, having to pay a deductible for about half the price.¹⁸

Private care is allowed to be present in the public realm of healthcare because it is believed that there are some cost saving advantages for the public administration. Additionally, it gives patients more freedom to choose their preferred care (Mori, 2015). The cost saving benefits could arise because accredited hospitals receive some private funding, providing care to patients, without taking too much money from the government, giving it back to the public hospitals. Additionally, they are taking some of the patients from the public hospitals, also providing cost saving benefits.

II. The Departments and Structure of the Hospital

As a rehabilitation hospital, Fondazione Santa Lucia provides a variety of neurorehabilitation programs to treat patients with both motor and cognitive deficits. Because the hospital is accredited, many of these health services are all provided under the SSN. Some of these therapies are designed to treat adult patients who have suffered from stroke, severe brain injuries (possible coma), spinal cord injury, and neurodegenerative diseases (Parkinson's, Alzheimer's, Multiple Sclerosis). Other programs treat children with rare genetic and developmental disorders. The hospital provides inpatient and outpatient services including extensive rehabilitation for children and adults recovering from cognitive and physical deficits ("Hospital.").

¹⁸ Observation June-July 2019.

The extensive rehabilitation at Santa Lucia is a complex care service, which is provided for under the SSN. Extensive rehabilitation is often included as part of the welfare services outlined in Article 26 of the constitution, which explicitly provides for health services aimed at assisting those with physical, mental or sensory disabilities achieve functional and social recovery. Those who qualify for this type of rehabilitation include children with a certified chronic disability from birth, as well as those who have suffered from a traumatic injury (“Extensive Outpatient Rehabilitation Unit.”). Although both adult and child extensive rehabilitation is provided at Santa Lucia, only pediatric care will be described here.

The Pediatric Extensive Rehabilitation Department is an outpatient center that provides holistic and individualized care to each child. The department’s team is made up of physicians, physiotherapists, speech therapists, psychologists, and providers of psychomotricity. Therapies include, but are not limited to physical therapy, speech and respiratory therapies, cognitive therapies, and psychological support. The diagnosis and therapy are monitored by the international standard assessment scales, including the biopsychosocial ICF approach (“Extensive Outpatient Rehabilitation for Children.”). This care is important since each child has a different disorder or issue to overcome. Furthermore, even if two children are diagnosed with the same disorder, they cannot be treated the same due to the complexity and diversity of symptoms for each case. The needs of the child determine the number of weekly sessions, the types of medical interventions, psychological support for the family, as well as school visits (“Extensive Outpatient Rehabilitation for Children.”).

This care provides yet another example of the holistic care present in Italy. Especially for children with disabilities, the care provided must take into account every facet of the child’s life, so much so that therapists and physicians will communicate with the school if necessary, making

sure the child's overall health, mental and physical, are taken into account. The parents are also included as active participants in any interventions by psychotherapists. This points towards Law 104/92, which, as mentioned, pushes for support of an individual so he or she can be integrated into society. Providing care that extends to the school system will give the child the support to do well in school with the goal of future advancement.

There are specific requirements, however, for a child to be admitted into Santa Lucia's rehabilitation program. Firstly, the disorders the program takes as president include cerebral palsy, severe prematurity, severe feeding and communication impairments, cognitive deficits, and rare genetic and chromosomal syndromes, such as Down Syndrome, Prader-Willi Syndrome, and Cri Du Chat Syndrome. If the child has one of these rare genetic disorders then he or she must begin treatment within the first two years after birth. If the child has a congenital disorder, then treatment must begin within the first 18 months. The department also accepts children who have an acquired disorder due to an event such as a traumatic brain injury, who also must begin treatment within the first 18 months following the event.

To begin this program, the child is required to have a public prescription by either a physician or by ASL. The prescription must specifically include the phrasing, "*Presa in carico riabilitativa in modalità estensiva per... [una specifica diagnosi]*" ("Taking in rehabilitation in an extensive way for ... [a specific diagnosis]"). This is given to the Office of Admission at Santa Lucia and then forwarded to the medical staff of the Pediatric Extensive Rehabilitation Unit. If accepted, the child is placed on a waiting list and the overall waiting time for admittance is usually three months or less. If the child does not fit within the criteria above, he or she is also placed on a waiting list, but because this rehabilitation program is in such high demand it is unlikely the child will be admitted ("Extensive Outpatient Rehabilitation for Children.").

It is also important to note that this high demand requires the department to review and must let patients go after a certain amount of time. Once a month there is a review of the patients who have carried out a six month rehabilitation program in order to evaluate each patient's progress. If the child is let go, the family can seek treatment from a public hospital. Parents do not necessarily react well to this because the care provided by the private hospital is generally better since private hospitals tend to have more specialized physicians and care than the public hospitals.¹⁹

As an internship location, I gained valuable insight into the structure of care for children with physical disabilities within the SSN. Santa Lucia provided information on both the public and private health sectors since it is accredited, making my understanding of the SSN more comprehensive. Additionally, because of how the hospital is structured, I was forced to also learn about the Italian legislation, which became an important component to my research.

4. Law 104/92

Finalità

1. La Repubblica:

- a. garantisce il pieno rispetto della dignità umana e i diritti di libertà e di autonomia della persona handicappata e ne promuove la piena integrazione nella famiglia, nella scuola, nel lavoro e nella società;
- b. previene e rimuove le condizioni invalidanti che impediscono lo sviluppo della persona umana, il raggiungimento della massima autonomia possibile e la partecipazione della persona handicappata alla vita della collettività, nonché la realizzazione dei diritti civili, politici e patrimoniali;
- c. persegue il recupero funzionale e sociale della persona affetta da minorazioni fisiche, psichiche e sensoriali e assicura i servizi e le prestazioni per la prevenzione, la cura e la riabilitazione delle minorazioni, nonché la tutela giuridica ed economica della persona handicappata;
- d. predispone interventi volti a superare stati di emarginazione e di esclusione sociale della persona handicappata. - Legge 104/92

Purposes

1. The Republic:

- a. *guarantees full respect for human dignity and the rights of freedom and autonomy*

¹⁹ Observation June-July 2019.

of the handicapped person and promotes their full integration into the family, in the school, work and society;

- b. prevents and removes the disabling conditions that prevent the development of the human person, achieving the maximum possible autonomy and participation of the disabled person in the life of the community, as well as the realization of civil, political and property rights;*
- c. pursues the functional and social recovery of the person affected by physical disabilities, psychic and sensory and ensures services and benefits for prevention, care and the rehabilitation of disabilities, as well as the legal and economic protection of handicapped person;*
- d. prepares interventions aimed at overcoming states of marginalization and social exclusion of the disabled person. - Law 104/92*

I. The History of the Handicapped Before and After Law 104/92

Prior to the advent of Law 104/92, the history of both the acceptance and neglect of the disabled is mixed, but what is evident is that for a long period of time there was no clear definition of the disabled or the rights they deserve. That is until Law 104/92 was put in place. There were many terms to define the disabled, such as *invalidi*, *disabili*, and *menomazioni fisiche e sensoriali* (invalid, handicapped, bearer of physical and sensory impairments), all meaning similar things, but at the same time not organized enough in legislation to clearly give rights to the proper group of people. Standardized terms such as, *portatore di handicap*, *personne handicappata* and *disabile*, which all refer to a person with a disability, did not come about until Law 104/92 (Massi, 3). Therefore, it is important to note that this particular law revolutionized how disabilities are defined both in legislation and in the medical field, as well as the obligatory rights and care of these individuals.

It is interesting to note that prior to the development of healthcare as an institution in the 15th century, people with disabilities were largely accepted within society. This included primitive and rural societies as well as societies in early Christianity and the Middle Ages. It was important to these individuals to perform charitable acts and take care of those in need (4). However, with the advent of an institution designed to take care of the sick, the hospital, the

every-day person may have begun to feel less obligated to go beyond his or her means to assist others. Modern society did not improve the situation of the handicapped; they were associated with the poor, outcast from the norms of society and the first institutional assistance they received was in fact mass reclusion for those who had mental and physical disabilities (4). This is completely the opposite of what Law 104/92 sets out to do, “full integration [of the handicapped] into the family, in school, in work and in society” (LEGGE 5 febbraio 1992 n. 104).

Finally, the theory, *assistenza come sicurezza sociale* (assistance as social security), developed, which began the use of the welfare state theory, when the state provides assistance to those in need (Massi, 4). In the 1890s and early 1900s, public assistance and charity institutions were established, but still the disabled were not referred to directly. Rather, these new initiatives were directed to the “poor and sick,” the category in which the handicapped were still placed. It was not until the 20th century that more changes were brought about and the state had to determine how to care for those who were injured in the war. This included needing to make proper health interventions, as well as providing for them economically. Slowly, more groups of people were added to those injured during war, such as those injured at work. The development of the idea of compensation began including pensions, invalidity checks, and free medical care (5). In the 1930s and 40s, there were well-defined groups of the disabled, defined by the physical handicap from which they suffered or illness from which they were recovering (7).

The Italian constitution also reaffirmed the rights of citizens and sought to set standards of equality for those with disabilities. Article 3 designated the Republic, or national government, with the task of removing, “economic and social obstacles that limit the freedom and equality of citizens, as well as an individual’s full development.” Article 34 was important in opening the

possibility of access to school and an education to everyone, making eight years of education obligatory and free. Thirdly, Article 38 gave the right of education and professional training to the disabled and handicapped.

However, just because these laws were written down, does not mean the transition was easy, and until the 60s, how categories of disabilities were defined and the access to their particular needs, including economic, healthcare, and job placement, did not align, causing some individuals to lack the support and assistance they needed. For example, economic assistance was given more often to the blind and deaf compared to others and the schools continued to allow there to be separation and differentiation between classes which were handicapped and non-handicapped (9).

Another turning point in the legislation was the advent of the Law of March 30th, 1971 n.118. This law demonstrates a change in legislators to focus on the rights of the disabled, putting more attention onto their integration. This law would be the basis for the framework of Law 104/92 (10).

Finally, in 1992, the Italian parliament approved a law for social assistance and the rights of disabled people, law 5.2.1992 n.104, or Law 104/92 (13). This law is not only important in that it further enhances the effort to integrate those with disabilities into society, but it also recognizes each person overall, starting from birth, as well as his or her place in the family, school, and work life (14-15). Law 104/92 pushed people to redefine what having a disability in society is, therefore allowing each individual to hold onto his or her dignity, rather than being marginalized (16). However, in order for this law to work, the national government, local administrators at the regional level, and members of civil society must recognize it so that the disabled can be integrated and feel that they are valuable members of society (18). This law

outlines all disabilities, both acquired and congenital. There are several factors that contribute to this idea of integration when it comes to a child with a physical disability. The care and rehabilitation of the child are of utmost importance, as well as the child's education, all of which are outlined carefully in Law 104/92.

II. Healthcare for Pediatric Disabilities

Law 104/92 makes the healthcare that children with physical disabilities receive more accessible because it defines the care to which they are entitled. Children with rare genetic disorders, or who are premature, have free healthcare including rehabilitation, ambulatory devices, and tests including X-rays. Coupled with the Italian constitution and the enactment of the SSN, Law 104/92 sets in place all that is necessary to support a child with a physical disability, allowing him or her to engage in society in a positive way.

Although the law outlines preventative measures for disabilities, including during pregnancy, it is important to note that once the child is born, the preventative measures are ongoing. During the neonatal period, for example, babies are monitored to ensure an early diagnosis of any malformations or congenital disorders. Additionally, the law outlines the use of vaccines as a preventative measure against any disease, especially rubella (61). For a child who contracts rubella, it usually does not cause severe side-effects, but if a mother were to contract it while she is pregnant, it can have lasting effects on the child such as deafness, heart defects, and growth retardation ("Rubella."). Therefore, it can be seen that this law also outlines ways in which to prevent disability before birth.

Rehabilitation is then made available to anyone with a physical disability and timely intervention is of the utmost importance. In Italy, rehabilitation is an integrative program, using both health and social services, involving the family and community. With this widespread

support, the child can strive for and therefore achieve more in society. According to Law 104/92, rehabilitation is important to improve the methods and opportunities for social integration. The law outlines not only “functional therapy” such as speech therapy or physical therapy, but also the importance of psychological support, both for the child and his or her family (Massi, 62). Having a child that has a disability can be very difficult, which is why it would be important for the parents especially to also receive guidance. The process to apply for this kind of treatment is as outlined in the process to apply to the program at Santa Lucia. A request is sent to the local ASL unit with a certificate of residence, as well as a medical certificate from the child’s pediatrician (63).

Another important aspect of care, especially for children with physical disabilities, is prosthetic assistance. This is what I found to be one of the most interesting parts about the Italian healthcare system, the fact that all equipment is provided for free to children with disabilities, by the SSN. Under Italian healthcare these aids are defined as, “tools, devices and technologies that prevent or reduce forms of disability... and improve the autonomy, mobility, communication and relationship skills,” of the individual. Some aids include prostheses and orthoses, personal care aids (clothing and footwear), and devices for mobility (63). Specifically, the devices and how much the government will contribute to pay for them is outlined in the legislation: the aids are paid in full by the SSN, technical devices such as mattresses and pillows are partially paid for by the SSN, and finally, devices used for respiratory and food assistance are paid in full by the local health units, which are funded by the SSN (64). In order for the child to gain access to these devices the same certificates must go to ASL and there must be a specified prescription for the device made by the physician overseeing the therapy. ASL will review this documentation and then determine if the device is reasonable for the patient (65).

This law however, can find practical difficulties in its application. Although the written legislation is well thought out in how it outlines its objectives in supporting the disabled in achieving autonomy and social integration. These difficulties lie in bureaucracy, as well as lack of resources in the health sector. The legislation is also not revised frequently enough to remain up to date with the current needs of patients, such as the rules in prescribing prosthetic devices. At times it can be difficult to provide the prescription if the needs of the patient are not clearly outlined in the legislation.

Additionally, it has been difficult to remove architectural barriers such as cars parking in front of accessibility ramps and broken elevators in subway stations. In order to overcome these obstacles, the institutional and social mindset must change by reminding people to consider those who have disabilities and their accessibility needs (Grasso, 79-80). After living in Italy for a total of six months, both in Perugia and Rome, and traveling to a few other cities and towns, it became clear that there were many architectural barriers are very difficult to remedy. Italy is a very old country with many historic buildings and roads, which can be difficult to alter without disrupting the preservation of important buildings and sites. Perugia is all hills and stairs, making getting around very difficult for anyone who has difficulty walking or uses a wheelchair. Other small towns, and even Rome, a city with more resources, have difficulties with the accessibility of certain streets. Transportation is also a problem. Buses have some accommodation measures set in place, but the trains are less accessible. Often, there are stairs to climb up from the platform rather than the train being level for easy wheelchair access. The isles are also tight. The metro is somewhat better, but there was an instance of an elevator at one station being out of service for over six months. These issues can make living in Italy very difficult for those with physical disabilities.

There are some movements to improve accessibility. One is to create a support network for the ill and their caregivers to optimize assistance and resources. Another is to develop computer aids to help individuals communicate, such as on computers, especially for those who cannot communicate verbally. This would greatly improve the quality of life of an individual as he or she would be able to contribute to society, solving complex problems, but also expressing daily needs (Grasso, 80). As seen there are some issues with the application of Law 104/92, but with the work of many dedicated health professionals, as well as the families of the disabled, and the patience and determination of these individuals with disabilities, change can happen.

III. Education

A more concrete example of how children with disabilities were excluded from society before updated legislation is their separation from the school system. Originally, students were completely excluded from the system and did not attend school. The second phase was separation, which means that children with disabilities could attend school, but they were separated from the other students into classes specialized for students with disabilities. However, these classes were in regular schools (Antenore). This separation could have caused great psychological stress on the child as he or she is made to feel different and abnormal compared to his or her peers. This would also impact the child's feeling of value within society, as well as the sense of ability to advance and achieve.

There was a push that began in 1971 to end the idea of separation and integrate students with disabilities into regular schools and classes, having a mix of peers. Then finally, there was a shift in the perspective of inclusion, valuing diversity among individuals (Antenore). This idea of inclusion manifests in a variety of ways in the classroom, but most importantly, it accepts each individual, abled and disabled, as the norm and makes room for all forms of participation and

learning styles (Antenore). There is also a new bio-psycho-social model which is used by the legislation on Special Educational Needs, placing health and disability on a continuum, which does not necessarily define a person with a disability as unhealthy, as previous models defined handicapped individuals (Antenore).

In Italy, education is a right through university level and this, therefore includes the right for handicapped individuals to have an education. Article 12, paragraph 4 of Law 104/92 clearly states, “the exercise of the right to education cannot be prevented by learning difficulties or other difficulties deriving from disabilities connected with disability.” This starts as young is 0 to 3 years of age in nursery school, or preschool. These schools are required to be able to adapt to the needs of a student with disabilities and be able to assign teaching staff and assistants to support the child (Massi, 102). Furthermore, there are also accommodations available to students who cannot attend school due to issues related to disability such as hospitalization (103).

There is also legislation on how to assist students and which disability merits the help from assistant teachers. The name of this is *Bisogni Educativi Speciali* (BES). Those with specific disabilities, such as cerebral palsy, are entitled to be certified to have a support teacher, as well as specific programs of learning. The other two categories of students are not entitled to a support teacher, but are eligible for accommodations. The first category is “specific evolution disorders,” which include disorders such as ADHD, and the second category is called “socio-economic disadvantage, linguistic, cultural,” these students are identified by social services and psychological assessment to determine if they need accommodations. The difference between these two groups, however, is that those with disorders are still certified under ASL, like those with disabilities, but the third group is not (Antenore).

There is a whole team involved in the integration of the student in the school system, including the family, the rehabilitation team, the people working at the school including the teachers and they all plan the objectives of the education of the student and how they can be reached. It is essential for the family to be involved because they are educated in how to take care of their child in how to use the necessary equipment and the best form of communication, both of which are vital for the teaching team to understand in order to best integrate the student into the classroom (Antenore).

The team of teachers then, is also imperative as they are the ones who determine the best way for integration. The head teacher, is the main teacher in the classroom who is teaching the material to all the students, those with and without disabilities. Therefore, it is his or her job to make integration smooth and provide an inclusive environment. The support teacher is an assistant to the head teacher, which helps with the inclusion of the student and carrying out teaching plans in the classroom. He or she uses specific strategies and aids to help the student learn based on his or her needs. The teacher is also vital in planning the educational program of the child with the other teachers, parents and rehabilitation team. The support teacher is a full teacher with a degree equivalent to a master's degree in education. The support teacher can also specifically help the child with a disability such as providing assistance on state examinations and mediating between the school, student's family, and the rehabilitation team. The third teacher that is important to discuss is the cultural education assistant, who is present when needed for a student to assist with communication, going to the bathroom, and help the student achieve autonomy in educational and recreational activities. These are the three main teachers, which are important to discuss in the support of a child with a disability in the school system. However, additional teachers can be provided if necessary for special communication or if the

child has limited vision. These teachers make up the *consiglio di classe* (council of the class), all working together in order to ensure the educational needs of the student are met, and he or she is properly integrated (Antenore).

These teachers, along with the head of the institute, the family and the rehabilitation team form a group called the “Institute Handicap Working Group,” which is responsible in making an individualized education plan for each student. There is one group for each student and one disabled child per classroom. This plan is based on the functional diagnosis of the student, which is the analysis of the child’s disability in order to ensure the proper plan is made for educational integration. Additionally, there is a functional dynamic profile, which is based on the child’s evaluation throughout the time spent at the school in order to ensure learning and integration is going well and the child is meeting developmental goals. The dynamic profile is also useful for the teacher in making modifications to teaching plans to improve accessibility to the material being taught. This group meets at least twice per year to review the progress of the student, as well as make any changes to the education plan if necessary (Antenore).

Although these steps are clearly thought out to ensure the best integration possible for each student, there are still some shortcomings the Italian educational system has not overcome. Of late there has been an increased presence of children with disabilities in the school system. In the 2015-2016 school year there were 156,000 pupils with disabilities in Italy. This increase since 2000 is most likely because there is an increased awareness of the inclusion of children with disabilities in the school system and their right to education. This influx of students has been a source of economic stress in these schools which lack enough resources to provide for this new influx. For example, the government a set number of support teachers that are required to be made available at each school based on the number of disabled students, as well as the severity

of their needs. There are also a limited number of hours that support teachers are made available to students during the week. For students in elementary school, support teachers are available for 22 hours per week and then 18 hours per week in secondary school. Many families want their children to be provided with more hours from a support teacher than are given. However, because of a lack of funding, schools are not able to meet the needs of their students.

Additionally, there is a lack of continuity for students who change their support teacher from year to year, or even during the academic year (Antenore). This can be an issue because it takes time to understand the situation for each child, his or her needs and how to best communicate. With the changing of these teachers, there is always going to be a learning curve, which can make integration slow and can be confusing for the child.

Another problem is that many school buildings have architectural barriers, meaning there are accessibility issues for children with disabilities. It is interesting to note that there is a regional divide in this area, with the South tending to have a higher percentage of facilities that are not up to code with the law for accessibility compared to the North, although the North still has problems, as well. Schools are also not working to fix these concerns even when they know it is necessary to make changes. The final issue to highlight is accessibility to technology. The methods of using computers are not accessible to students, with unsuitable workstations including hardware and software specific for special education students. The South again was found to have poorer scoring, but the North had higher ratings in this category (Antenore).

The main takeaway from these disparities and accessibility issues is the need to investigate economic issues in the school system, as well as the need for flexible organization. The issues to be rectified are the poor presence and use of technology, the insufficient preparation of teachers, teaching continuity, architectural barriers, distribution of support and

assistance hours, and finally the limited participation of students in educational trips. The decline in economic resources for schools have already been seen to be detrimental to students with disabilities. Some solutions to these issues surround the idea that there should be a team approach to best help the student among the family, school, and rehabilitation team with the sharing of ideas and better training for teachers in order to best make a school environment adapted to the needs of the student and that integrates the BES program well. The ultimate goal of course is transitioning the child into inclusion, which ultimately means accepting the child with a handicap into a “normal reality,” allowing him or her to recognize personal strengths and to use his or her abilities (Antenore).

5. Case Study

In order to further investigate the healthcare of children with physical disabilities, I decided to include a case study of a child with cerebral palsy (CP) at Fondazione Santa Lucia. By including a case study, the actuality of Law 104/92 can be analyzed in how it affects the care of a particular individual and if it is meeting its goals rather than looking at statistics or other forms of documentation. Additionally, it better demonstrates the holistic nature of the Italian healthcare system. Looking at a case study revealed the pitfalls of public initiatives, including funding and staffing issues.

This particular case study is of a boy aged 12 who has CP. CP is a muscular disease that causes limited motor functioning in the limbs and other parts of the body. There may be difficulty in speaking and eating, as well as intellectual disability, although the symptoms vary between individuals. Diagnosis of CP usually occurs when the child is not meeting developmental milestones, so he has been living with CP his whole life.

The patient was born at 29 weeks and 6 days, with reported suffering with a low Apgar score indicating poor health. He was born with a twin brother, who had a very high Apgar score indicating good health, but he contracted a pulmonary infection and later passed away.²⁰ The patient began rehabilitation at Santa Lucia at the age of 4 months in compliance with the acceptance criteria of the hospital. Physical rehabilitation began with practical functional taping, which blocks the use of certain muscles while enforcing the use of others to strengthen them. Other forms of therapy he has undergone include hydrotherapy, speech therapy, and occupational therapy. Although he has a great command of language and has a high IQ, because of his disability, he has trouble producing language, which is why he has undergone speech therapy. He also uses a speech text computer to help him communicate. As far as devices, the patient uses orthosis for upper limbs. He was also prescribed an NF walker.²¹ This is a walker that allows the user to be strapped in so he can be upright in a standing position with support and he can walk by moving his legs which are attached to pulleys that cause the wheels on the walker to move. This is a great device for those who are wheelchair bound because it helps with digestion, posture, muscle strength, and body alignment.²² He started using the walker in rehabilitation sessions, but then was using it at home for 2 hours per day. He was also using it at school, but when the hours of his cultural support teacher were reduced, he could no longer use the walker at school.²³ This, therefore is a demonstration of how the reduction in hours of teaching assistance can negatively affect the care of a child with a disability. Overall, the therapy now includes two sessions of neuro-motor therapy per week, one occupational therapy session, one fonologopedia, and one

²⁰ Medical chart, July 2019.

²¹ Medical chart, July 2019.

²² Observation June-July 2019.

²³ Medical chart, July 2019.

psychological therapy session per week.²⁴ It is important to remember that these devices, treatments, and therapy sessions are all covered under the national healthcare system. Because the patient has a debilitating disorder, his care is obligated to be free of charge, so he is treated and his family does not have to worry about paying for his care.

It is also necessary to discuss the patient's psychological condition in brief because it demonstrates how important the aspect of integration outlined in Law 104/92 is, as well as how downfalls in the school system can negatively affect the child. As the patient grew up he became very aware of his situation and compared himself to his peers. He has dealt with anxiety and depression because of it. When he went to kindergarten in 2012-2013 he experienced good integration and attended school activities. After this he went to elementary school and had a similarly positive experience. However, at the age of 5 he started to have episodes of nausea and vomiting which were later linked to anxiety and depression. He changed schools a few times because he was not happy and did not integrate well. In one particular school he felt the teachers were not treating him as if he was intelligent enough and they did not appear to adapt well to his needs.²⁵ It is possible that this particular school was suffering from a lack of funding and therefore could not adequately provide for his needs. As previously stated, a lack of financial resources can have a direct negative effect on the care of the child if he or she does not feel that adequate support is being given. Once he switched to his current school, however, he became much happier and his performance at school improved. He integrated well with the other students and his requests to leave class were less frequent²⁶, which shows his social anxiety decreased. He is also sought after by his peers for help with homework²⁷ demonstrating his

²⁴ Medical chart, July 2019.

²⁵ Medical chart, July 2019.

²⁶ Medical chart, July 2019.

²⁷ Medical chart, July 2019.

autonomy among the other students. He also is found to participate in a variety of activities outside of school. This includes pool practice privately once per week with *la Federazione Italiana Nuoto*. Additionally, he has participated in a summer camp organized by the spina bifida association and attended the next year as well; it was a positive experience. He was also involved in theater classes once a week.²⁸ These activities, as well as how the patient participates in school are clearly very important to his health, especially in the case of this boy because of his awareness of his condition and his desire to feel he has the ability to do things. This is why the push to help children with physical disabilities such as with this patient is important in order to achieve social integration and autonomy as outlined in Law 104/92. The negative effects of feeling as if one does not belong are evident in this particular case. When the patient felt he was an outcast from his peers he developed psychological stress including anxiety and depression.

Overall, this case study is a good demonstration on the effectiveness of Law 104/92. As far as healthcare, the patient appears to have good quality of care. Although, when asked what he thought of the healthcare system by one of the therapists, he gave her a look to say that he had some grievances. However, he has access to rehabilitation as well as other therapeutic treatments and is provided with the devices he needs. On the other hand, the school system has been a difficult experience for him, which can be attributed to a lack of funding and unequipped teachers. This patient's experiences are a good comparison to the description of the objectives of Law 104/92 and the pitfalls it can have in practical application.

6. Conclusions

Il Servizio Sanitario Nazionale is an incredibly complex healthcare structure. However, what makes it such an interesting template to study is that the Italian citizens have access to care

²⁸ Medical chart, July 2019.

as a fundamental right under the constitution. They pay very little for care and the quality of care is good. It is actually one of the highest ranked healthcare systems. When speaking with various Italians about their healthcare, they always talked about how good it is and how happy they are with the care they receive. I heard this even from a woman living in the South.

The allocation of money seems to be the most difficult hurdle to overcome, especially due to regional disparities. The lack of resources limit the ability of the legislation laid out to meet its goals. Even still, to go to a hospital and receive decent care without having to worry about the bill, especially when it is an emergency, is something of a novelty to someone from a country where healthcare is largely privatized. Generally speaking, the Italian healthcare system is effective.

Law 104/92, the subject of this paper, is largely affected by the downfalls of social structures and poor funding. The distribution of funds to hospitals by the government will directly affect the care of children with physical disabilities due to the lack of hospital resources. These funding issues also affect the education of students with disabilities, negatively affecting their integration within society. Despite these disparities, however, the legislation is comprehensive and was revolutionary in restructuring the care of the handicapped. It is a foundational document for any healthcare provider working with individuals with disabilities, including the Pediatric Extensive Rehabilitation Center at Fondazione Santa Lucia. The providers at this hospital do their utmost to provide excellent care to their patients, further demonstrating that despite infrastructural issues, quality care is still available and strived for.

The case study of the patient from Santa Lucia clearly demonstrates the good quality of care in Italy for children with disabilities; free rehabilitation, tests, doctor's visits and equipment

in a private hospital. However, the pitfalls of the education system were clear in its negative impacts.

A confounding variable in this study is that much of the research is based on a private hospital in Rome. A private hospital will be better resourced than a public one, with fewer gaps in care and more financial resources. The location of the hospital is also a benefit as it is in a large city with easier access to resources compared to hospitals further removed from urban settings. Rome is also further North and hospitals may be less affected by regional issues in money allocation by the government. However, further investigation may look at rehabilitation programs in purely public hospitals, as well as those in hospitals in the country and the South to determine if this conclusion would be the same and if the South really would have a decrease in quality of care. The parameters of this study, however, contribute to an overall positive review of the healthcare system in Italy, as well as the effectiveness of Law 104/92.

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